

In re) Fair Hearing No. B-04/15-450
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 Appeal of)

Petitioner appeals the proposed termination of her son's eligibility for "Katie Beckett" Medicaid by the Vermont Department for Children and Families ("Department"). The following facts are adduced from the written filings of the parties.

1. Petitioner's son ("T.") has a rare genetic disorder called Mucopolysaccharidosis Type I ("MPSI"). He is six years old and received this diagnosis when he was approximately two and a half years old. At that time, the severity of MPSI was differentiated by syndrome; T. was diagnosed as having "Scheie" syndrome, as compared to the more severe "Hurler's" syndrome. Under an apparently new nomenclature for MPSI diagnoses, T. is currently diagnosed as having "attenuated" MPSI, replacing the term "Scheie."

2. MPSI is understood as a result of an inability of the body to sufficiently produce an enzyme that breaks down

"glycosaminoglycans" ("GAGs"), a compound that - if it builds up - eventually causes significant joint, tissue and organ damage. The severe form of MPSI can lead to death during childhood; attenuated MPSI may or may not lead to premature death.

3. Whether severe or attenuated, MPSI presents serious health risks, including: heart valve abnormalities; hydrocephalus (fluid buildup in the brain); enlarged liver, spleen, tongue and vocal cords; pulmonary difficulties; corneal clouding resulting in vision loss; short stature and joint deformities, including compression of the spine and carpal tunnel syndrome; decline/regression in intellectual functioning; and learning and developmental disabilities. The condition often causes "coarseness" in features and an enlarged head. T. has facial coarseness as well as enlargement of his tongue and some organs.

4. Around age 2 years and 9 months, in August of 2011, T.'s parents took him to an out-of-state genetic specialty clinic for a consultation. T. was diagnosed with MPSI "Scheie" syndrome at that time and was noted to be doing well in light of his diagnosis. His development in almost every area was found to be normal or above average, with the

exception of his gross motor skills, which were rated as "slightly below average."

5. The genetic consultation concluded that T. would need continuing follow up for potential medical issues as he was "at risk in the future for cognitive, cardiac, and orthopedic problems, even though they are not seen at present." (emphasis in original) At the time, the consult report emphasized monitoring T.'s hearing (as he had already had a Tympanostomy/PE tube placed in one ear, to address fluid build-up), continued occupational and physical therapy, and continued enzyme replacement therapy. By this time T. had also successfully undergone an umbilical hernia repair.

6. Enzyme replacement therapy is a potential medical intervention for the underlying cause of MPSI. T. initially underwent this treatment in a medical facility and his parents were eventually taught how to perform the therapy at home. He currently receives five hours of enzyme replacement therapy, all in one session at home, per week. He has an IV port placement in order to receive the enzyme replacement therapy.

7. By decision dated October 4, 2011, the Department determined that T. was disabled under Social Security Administration standards. Specifically, he was found to

"medically equal" listing 110.08, with the following explanation:

Child recently diagnosed with mucopolysaccharidoses, scheie syndrome, although currently doing well with regards to development noted to have umbilical hernia and enlarged liver and spleen. Evaluated and not felt to be a candidate for bone marrow transplant but has port in place and to get weekly enzyme infusions in an attempt to slow down expected progression. Is currently being seen by multiple services in order to follow developmental and hearing and vision that are expected to become problematic. Medically equals listing, would reassess in 2-3 years for progression.

8. Following the finding of "disability" under SSA standards, T. was also found "Katie Beckett" eligible for Medicaid.

9. In the intervening years, since this eligibility decision, T. has had a tube placed in his other ear, has had two operations for carpal tunnel syndrome in his wrists, has experienced persistent problems with his ears, and has been diagnosed with "corneal clouding" in his eyes, causing vision problems. He has been diagnosed with attention deficit hyperactivity disorder ("ADHD") and receives special education services. T. continues to receive occupational and physical therapy on a weekly basis at school and daily basis at home. As noted above, he continues to receive enzyme replacement therapy administered at home five hours per week through an IV port.

10. T. is followed medically in a variety of areas. Because of nerve damage in his wrists, which led to the need for carpal tunnel surgery as well as muscle degeneration, stiffness and clubbing of his hands, he sees a hand surgeon twice a year. It is estimated that he will need carpal tunnel surgery on both wrists again in the next 1-2 years. Because of buildup of GAG in his ear, nose, mouth and throat, T. has chronic ear infections at an average of two per month. He is seen twice a year by an otolaryngologist for a hearing test and examination. He also sees the otolaryngologist and his pediatrician on a regular basis to treat his ear infections. As noted above, T. has undergone PE tube placement, has had one recently removed, and will need new tubes placed again within the next year.

11. T. sees an ophthalmologist twice a year to address his corneal clouding and resulting visual deficits, for which he wears glasses and which will eventually lead to the need for a corneal transplant. The corneal clouding reduces his sight in dim light and tolerance for bright lights, as well as causes an astigmatism and accommodative esotropia (crossed eyes). T. also sees an orthopedic surgeon once a year for evaluation due to slippage in his vertebrae, causing a curve in his spine. Thus far this condition has not required

surgery. In addition, T. sees an orthopedist once a year to monitor stiffness and abnormal mechanics in his hip joint which are at risk of worsening over time.

12. T. sees a cardiologist once per year to monitor a variety of problems with his heart and related arteries, which place him at risk for heart disease. He also sees a pulmonologist annually to monitor problems with his pulmonary system, including compression of his lungs because of his enlarged liver and spleen, as well as GAG buildup in his airways.

13. T. is seen by three different genetic specialists, two of whom are out-of-state, once (each) per year, for evaluation and testing. This includes a "sedated" MRI and CT scan, to monitor for a risk of hydrocephalus that can lead to brain damage. He also receives annual cognitive testing.

14. Due to his ADHD, T. sees a psychiatrist every four months and takes two prescribed medications. He has an echocardiogram every six months to monitor potential effects of the medication on his heart.

15. In the aggregate, T. sees approximately 13-14 physicians and specialists on a regular basis, as well as his occupational and physical therapists on a weekly basis. This represents a myriad of ongoing medical issues as well as

preventative care for a variety of potential medical issues, as described above.

16. T.'s most recent out-of-state evaluation, from July of 2014, again notes that he is doing well in light of his diagnosis. Cognitive testing showed lower scores compared to T.'s 2011 testing, a decrease which is attributed as likely due to his ADHD. The report recommends continuing the treatment interventions and monitoring in place, as "[g]iven his medical history, it is important that [T.] receive the *maximum* amount of therapeutic intervention possible because even if he demonstrates intact skills, his medical condition places him at risk for difficulties in maintaining those fine skills and gaining other skills," as well as that "he is at risk for problems in several aspect [sic] of his health, even if they are not seen at present." (emphasis in original) The July 2014 report is, without dispute, credible and relied upon by both the Department and petitioner.

17. Similarly, both T.'s pediatrician and Vermont-based geneticist provide (in identical written statements) that "[i]t is only through the combination of daily, weekly, monthly and yearly intensive and regular medical treatments,

interventions, medications and surgeries that he is able to maintain his quality of life.”¹

18. In reviewing T.’s continued eligibility for Medicaid, the Department determined that he “[d]oes not appear to continue to meet listing 110.08” and found that he only had a marked impairment in one area of functioning, that of “Attending and Completing Tasks,” as a result of his ADHD. The following summarizes the Department’s determination as to each domain of functioning:

- a. “Acquiring and Using Information” – No limitation, based on T.’s cognitive testing and academic performance.
- b. “Attending and Completing Tasks” – Marked limitation, based on reports of T.’s pediatrician and the July 2014 evaluation mentioned above.
- c. “Interacting and Relating With Others” – No limitation, based primarily on speech-language evaluations.

¹ The Department appears to take issue with the uniformity of the pediatrician’s and Vermont geneticist’s statements. While the statements are identical, they are deemed credible because they are highly consistent with all other medical evidence in the record, as well as the opinion of the out of state consultant described in paragraph 16, *supra*.

d. "Moving about and Manipulating Objects" - Less Than Marked Limitation, based on physical limitations caused by T.'s MPSI.

e. "Caring For Yourself" - No limitation, with the notation "None due to Psych MDI."

f. "Health and Physical Well-Being" - no limitation, with the notation "None due to Psych MDI."²

19. The Department's decision further concludes that T. was "doing well" but "expected to have significant delays in development" at the time he was initially found eligible, and acknowledges the development of his ADHD and other medical problems - such as carpal tunnel syndrome, corneal clouding, joint stiffness, ear infections, continued limitations in fine and gross motor skills - as well as the ongoing monitoring of his medical condition in the intervening years.

20. After determining that T. is no longer disabled, the Department notified petitioner that - based on that determination - T.'s Medicaid eligibility would be terminated.

² Although not material to the outcome, it is concluded from the accompanying medical records that "psych MDI" refers to the term "psychological medically determinable impairment."

21. In reviewing additional medical information submitted by petitioner after this fair hearing was requested, the Department issued an updated determination maintaining that T. is no longer disabled, citing "medical improvement" as the basis for the decision.

22. It is found, based on the medical record submitted and described above, that T. has not experienced medical improvement of his impairment(s).

ORDER

The Department's decision based on its determination that T. is no longer disabled is reversed.

REASONS

Review of the Department's decision is de novo. As this concerns a termination of Medicaid eligibility, the Department has the burden of establishing, by a preponderance of evidence, the appropriateness of its decision under the applicable rules. The sole basis of the Department's decision was its determination that T. is no longer "disabled" under the rules.

"Katie Beckett" Medicaid eligibility waives income and resource standards for children who meet Social Security Administration (SSA) disability standards and require the

same level of care as that provided in a "medical institution." Health Benefits Eligibility and Enrollment ("HBEE") § 8.05(k)(6). The cost of care for the child in the community cannot be more than what the cost would be in an institution. See Id.

Medical Improvement Standard

Once an individual is found disabled under SSA standards, they are subject to periodic continuing disability reviews. To find a child no longer disabled, the applicable laws, regulations, and SSA rules require a finding of "medical improvement" (absent any applicable exception to medical improvement, which is not at issue here) and that "the child's impairment(s) no longer results in marked and severe functional limitations. . . ." SSA Program Operations Manual System (POMS) DI 28005.001; see also 42 U.S.C. § 423(f); 20 C.F.R. § 404.1594.

The rules are clear that if there is no medical improvement, then "disability will be found to continue." 20 C.F.R. §404.1594(f)(5). Medical improvement is defined as:

Medical improvement is any decrease in the medical severity of your impairment(s) which was present at the time of the most recent favorable medical decision that you were disabled or continued to be disabled. A determination that there has been a decrease in medical severity must be based on changes (improvement) in the

symptoms, signs and/or laboratory findings associated with your impairment(s) (see §404.1528).

20 C.F.R. § 404.1594(b)(1).

The Department argues that the evidence supports a finding of medical improvement. This is based on the fact that, by all accounts, T. is doing as well as his peers in many areas of functioning, with the exception of “attending and completing tasks” due to his ADHD. However, the Department’s determination fails to address the fact that T. was doing just as “well,” if not better, when he was initially determined eligible. The rules clearly require the finding of medical improvement to be *relative to the “most recent favorable medical decision” of disability.* See 20 C.F.R. § 404.1594(b)(1), *supra*.

If anything, the evidence establishes that T. has experienced a range of medical and developmental issues since his last favorable eligibility determination, such as his ADHD, carpal tunnel surgery, and corneal clouding. T. generally performed worse, not better, on his cognitive testing, despite meeting most developmental milestones. Moreover, the evidence is undisputable (and certainly not rebutted by the Department) that T. remains at serious risk of deterioration medically and developmentally because of his

underlying condition. There is no evidence this risk has improved, nor does the Department argue that it has.

For these reasons, the evidence does not support a finding of medical improvement as urged by the Department.

"Functionally Equaling" the Listings

Even assuming a finding of medical improvement, in order to be determined no longer disabled, one's impairment(s) must also be found to no longer result in "marked and severe functional limitations." See SSA POMS DI:28005.001, *supra*. The general approach to making disability determinations is to consider whether the person's impairment(s) is "severe," which is not disputed here, and if so, whether such "meets," "medically equals," or "functionally equals" a listed impairment. See 20 C.F.R. §§ 416.925, 416.926, and 416.926a. It is the last area of determination which is at issue.

In order to "functionally equal" the listings, the person's impairment(s) must result in "marked" limitations in two domains of functioning or an "extreme" limitation in one domain of functioning. There is no dispute that T. has a marked impairment in at least one domain of functioning, "Attending and Completing Tasks." This is the only domain of

functioning that the Department determined to be markedly limited.³

Petitioner argues that the evidence establishes T. has a marked limitation in "Health and Physical Well-Being," citing T.'s frequent medical appointments with several different specialists and other physicians, daily physical and occupational therapy, weekly five-hour intravenous enzyme replacement therapy, ear infections, visual deficits, and joint stiffness, ADHD symptoms and treatment, as well as numerous surgeries. The Department's medical evidence does not directly address or rebut this evidence, with the only explanation being that there is no impact in this domain "due to psych MDI."

As an initial matter, the Department's general position that T. performs comparably to his peers is not a factor in this domain, as under the rules:

Unlike the other five domains of functional equivalence (which address a child's abilities), this domain does not address typical development and functioning. Rather the "Health and physical well-being" domain addresses how such things as recurrent illnesses, the side effects of medication, and the need for ongoing treatment affect a child's body; that is, the child's health and sense of physical well-being.

74 Federal Register 7525 (2/17/2009).

³ The six domains of functioning are outlined in paragraph 18 of the findings of fact.

Federal rules also consider a "marked" limitation in this domain to include when a child is "frequently" ill or has "frequent exacerbations" of the impairment that result in "significant symptoms or signs," with "frequent" defined as episodes "that occur on an average of 3 times a year . . . each lasting 2 weeks or more" or "episodes that occur more often than 3 times in a year . . . but do not last for more than 2 weeks." 20 C.F.R. § 416.926a(e)(iv).

Not only does this domain include consideration of the physical effects of a child's impairment, it can include whether the child is "medically fragile" and needs "intensive medical care to maintain [their] level of health and physical well-being." 20 C.F.R. § 416.926a(l)(4)(v).

Petitioner is correct that the evidence clearly establishes T. experiences a wide range of medical issues and medical interventions, varying in seriousness, frequency and duration. In particular, T.'s ongoing joint stiffness which has led to carpal tunnel surgery, his eye and ear issues, and his five-hour weekly intravenous enzyme replacement therapy must be considered significant. To the extent that medical intervention has mitigated the frequency and duration of these issues, and prevented the development of other issues,

the rules clearly take that into account through the consideration of "medical fragility."

In that respect, T.'s need for ongoing and intensive medical intervention to maintain his health is uncontroverted. At six years old, among other things, he has already undergone several surgeries, is likely to need additional surgeries in the near future, must regularly see numerous in-state and out of state specialists to monitor his health, receives daily PT and OT, has frequent ear infections and worsened vision, and receives several hours of IV-based treatment every week. This is a level of medical fragility and impact on his physical health that is "marked," at a minimum.

For these reasons the Department's decision is inconsistent with the rules and the Board must reverse. See 33 V.S.A. § 3091(d); Fair Hearing Rule No. 1000.4D.

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